



# *Cost, Coverage, Care*

Judd Gregg (NH)  
Chairman

*Personalized Solutions to America's Health Care Challenges*

**STATEMENT OF SEN. JUDD GREGG  
REGARDING GENETIC NONDISCRIMINATION BILL  
February 16, 2005**

MR. PRESIDENT,

FIRST I WANT TO RISE TO CONGRATULATE THE SENATOR FROM WYOMING FOR ASSUMING THE CHAIRMANSHIP OF THE HELP COMMITTEE AND FOR MOVING FORWARD ON THIS EXCEPTIONALLY IMPORTANT PIECE OF LEGISLATION, GENETIC INFORMATION NONDISCRIMINATION ACT OF 2005. THIS IS A PIECE OF LEGISLATION WHICH BY MOVING IT FORWARD QUICKLY SHOWS THE PRIORITY THAT THE SENATOR FROM WYOMING PLACES ON STRAIGHTENING OUT OUR MEDICAL SITUATION IN THIS COUNTRY, MAKING DELIVERY OF HEALTH CARE IN THIS COUNTRY MORE AFFORDABLE, MORE THOUGHTFUL, AND IN THIS CASE, FREE OF DISCRIMINATION. **THIS IS THE FIRST CIVIL RIGHTS ACT, REALLY, OF THIS CENTURY, FOR ALL INTENTS AND PURPOSES. IT IS A MAJOR COMMITMENT TO THE PEOPLE OF OUR COUNTRY THAT THEY WILL NOT BE DISCRIMINATED AGAINST ON THE BASIS OF THEIR GENETIC CODE.**

LAST YEAR WE CELEBRATED THE DISCOVERY BY DR. WATSON AND DR. CRICK OF THE DOUBLE HELIX AND THEN WE ALSO CELEBRATED THE FACT THAT N.I.H. HAD MAPPED THE HUMAN GENOME; THE DNA PROJECT WAS COMPLETED. THOSE WERE HUGE MILESTONES WHICH HAVE HAD AN EXCEPTIONAL IMPACT ON THE QUALITY OF HEALTH CARE IN THIS COUNTRY AND WILL CONTINUE TO HAVE AN EXPANDING IMPACT WHICH CAN'T EVEN BE PREDICTED ON ITS BREADTH AND DEPTH OF INFLUENCE ON HOW WE DELIVER HEALTH CARE AND HOW PEOPLE'S HEALTH CARE IS EFFECTED IN OUR NATION. BECAUSE IF YOU CAN DEFINE WHAT OUR GENETIC CODE IS, YOU CAN MAKE HUGE STRIDES ON CURING DISEASES THAT MIGHT POTENTIALLY OCCUR TO ANYONE.

BUT THIS NEW SCIENCE CREATED ISSUES FOR US, PUBLIC POLICY ISSUES. ONE OF THE BIG PUBLIC POLICY ISSUES IT HAS CREATED IS THE ISSUE OF DISCRIMINATION BASED ON YOUR GENETIC PROBLEM. EVERYBODY HAS THIS PROBLEM, OR THIS BENEFIT OR THIS SITUATION. WE ALL HAVE GENES. IT'S A UNIVERSAL ISSUE. IT'S SOMETHING THAT IMPACTS EVERYONE. SO THE CONGRESS HAS TAKEN A LONG AND IN-DEPTH LOOK AT HOW WE SHOULD ADDRESS THIS FROM A PUBLIC POLICY, HEALTH POLICY STANDPOINT, IN WORKING IN A VERY BIPARTISAN WAY UNDER THE LEADERSHIP OF SENATOR ENZI.

PRIOR TO THAT, I WAS CHAIRMAN OF THIS COMMITTEE AND WE WORKED ON THIS VERY AGGRESSIVELY WITH HELP ACROSS THE AISLE FROM SENATOR KENNEDY AND MEMBERS OF THE DEMOCRATIC LEADERSHIP ON THE COMMITTEE. OUTSIDE THE COMMITTEE ITSELF SENATOR FRIST AND SENATOR SNOWE AND OTHERS HAVE PLAYED A MAJOR ROLE IN MAKING SURE THAT WHAT WE DID IN THIS AREA WAS THOUGHTFUL AND IT HAD A PURPOSE AND AN ACCOMPLISHED GOAL WHICH WAS TO MAKE SURE THAT DISCRIMINATION DOES NOT OCCUR AND THAT SCIENCE THAT THE HUMAN GENOME IS GOING TO PRODUCE COULD BE BEST IMPLEMENTED. AND WE DIDN'T END UP RETARDING THE DEVELOPMENT AND CREATION OF NEW CURES OR WAYS TO ADDRESS CONCERNS OF PEOPLE RELATIVE TO THEIR GENETIC HISTORY AND THEIR POTENTIAL THAT IT HAS FOR THEM AS THEY MOVE FORWARD IN THEIR LIFESTYLE HAD IT BEEN IMPACTED

NEGATIVELY BY ACTS OF DISCRIMINATION WHICH MIGHT CHILL PEOPLE'S WILLINGNESS TO USE THIS GENETIC INFORMATION OR TO OBTAIN THIS GENETIC INFORMATION IN THEIR INTERFACING WITH THE HEALTH COMMUNITY.

**SO THIS ACT IS AN ATTEMPT AND IS AN EFFORT AFTER A TREMENDOUS AMOUNT OF WORK TO THOUGHTFULLY AND INTELLIGENTLY ADDRESS THE ISSUE OF HOW WE EFFECTIVELY PROMOTE THE USE OF THE INFORMATION AND ACTUALLY ENCOURAGE PEOPLE TO TAKE ADVANTAGE OF THE NEW SCIENCE RATHER THAN AN ATMOSPHERE WHERE PEOPLE ARE DISCOURAGED FROM TAKING ADVANTAGE OF THIS NEW SCIENCE.**

WE KNOW THE POTENTIAL IS THERE AND WE HAVE INSTANCES OF IT. FEW, I MIGHT ADD, BUT SPECIFIC INSTANCES OF DISCRIMINATION OCCURRING BECAUSE OF A PERSON'S POTENTIALLY GENETIC HISTORY IN THE AREA OF EMPLOYMENT OR IN THE AREA OF HEALTH INSURANCE. THIS IS WHERE THIS BILL ADDRESSES THOSE CONCERNS. IT SPECIFICALLY ADDRESSES THE ISSUE OF HEALTH INSURANCE UNDERWRITING AND IT SPECIFICALLY ADDRESSES THE ISSUE OF EMPLOYMENT. ITS IMPACT IS THAT HEALTH INSURANCE PLANS WILL NOT BE ABLE TO DENY ELIGIBILITY OR ENROLLMENT BASED ON GENETIC INFORMATION AND IT PROHIBITS HEALTH INSURANCE PLANS FROM CHARGING HIGHER PREMIUMS BASED ON AN INDIVIDUAL OR FAMILY GENETIC INFORMATION--VERY IMPORTANT.

IT ALSO DOES NOT ALLOW AN INDIVIDUAL HEALTH INSURANCE EMPLOYER TO REQUEST GENETIC INFORMATION OR TO USE A PERSON'S GENETIC INFORMATION IN THEIR DECISIONS ON HIRING AND FIRING OF AN INDIVIDUAL. IT RECOGNIZES THAT ALL INDIVIDUALS WHETHER THEY ARE HEALTHY OR SICK AND ALL MEDICAL INFORMATION WHETHER GENETIC OR OTHERWISE SHOULD BE AFFORDED THE SAME PROTECTION UNDER THE LAW. THAT IS A CRITICAL POINT. THE PRACTICAL IMPLICATION OF IT IS THAT IF YOU'VE GOT A FAMILY HISTORY WHERE YOU MAY THINK THAT THERE MAY BE A PROBLEM THAT YOU HAVE BECAUSE OF YOUR GENETIC MAKEUP, YOUR WILLINGNESS TO GO FORWARD AND BE TESTED, YOUR WILLINGNESS TO SEE A DOCTOR TO SEE IF THAT GENETIC PROBLEM MAY ACTUALLY EXIST FOR YOU IS NOT GOING TO BE LIMITED BECAUSE YOU ARE NOT GOING TO BE CONCERNED WITH THE FACT THAT IF THIS INFORMATION COMES FORWARD OR IS OBTAINED IT MIGHT BE USED TO LIMIT YOUR ABILITY TO GET A JOB, KEEP A JOB OR GET HEALTH INSURANCE OR KEEP HEALTH INSURANCE, OR ALTERNATIVE THAT YOUR CHILDREN OR YOUR CHILDREN'S CHILDREN MIGHT ALSO IF THE GENETIC INFORMATION IS CONFIRMED, BE SUBJECT TO DISCRIMINATION FOR WORK OR FOR OBTAINING INSURANCE.

SO IT WILL ALLOW PEOPLE TO BE MUCH MORE AGGRESSIVE IN USING THIS BRAND NEW SCIENCE TO ASSIST THEM IN GETTING THEIR HEALTH IN ORDER AND MAKING SURE THEIR CHILDREN ARE PROPERLY SCREENED FOR WHAT CAN BE PRODUCED FROM GENETIC INFORMATION. THIS IS GOING TO BE SUCH A HUGELY VALUABLE TOOL FOR OUR SOCIETY AND OUR PEOPLE THAT THERE SHOULD BE NOTHING IN IT THAT SAYS TO PEOPLE YOU CAN'T AFFORD TO DO THIS BECAUSE YOU SEE THIS DOCTOR, IF YOU HAVE THIS TYPE OF REVIEW, YOU ARE GOING TO FIND OUT SOMETHING THAT MIGHT LEAD TO YOUR QUALITY OF LIFE BEING DRAMATICALLY REDUCED BECAUSE YOU LOSE YOUR JOB OR YOU LOSE YOUR INSURANCE.

SO THE LEGISLATION IS APPROPRIATE. THOSE WHO QUESTION ITS NEED, I THINK, DO SO OUT OF LEGITIMATE CONCERN THAT IT'S ANOTHER -- IT'S A NEW GOVERNMENT LAW, NEW FEDERAL LEGISLATION, AND THEY DON'T SEE THAT THE PROBLEM EXISTS, I GUESS, IN MANY INSTANCES, OR IF IT DOES EXIST THEY DON'T THINK IT'S SIGNIFICANT ENOUGH TO ADDRESS.

**I WOULD SAY THIS: YES, THE PROBLEM DOES EXIST. YES, WE'VE HAD INSTANCES OF DISCRIMINATION OCCURRING BOTH IN THE WORKPLACE AND IN THE INSURANCE COMMUNITY. THEY'VE BEEN LIMITED AS I MENTION, BUT MORE IMPORTANTLY THAN THAT, THIS IS A SCIENCE THAT HOLDS SUCH A TREMENDOUS POTENTIAL FOR DRAMATICALLY IMPROVING THE WAY WE DELIVER HEALTH CARE AS A SOCIETY, WE DON'T WANT TO STAND IN ITS WAY, CHILL ITS USE OR UNDERMINE THE WILLINGNESS OF AMERICANS TO PARTICIPATE IN STUDIES.**

SO IT IS AN APPROPRIATE PIECE OF LEGISLATION AND I THINK IT PUTS EMPHASIS IN THE RIGHT PLACE, WHICH IS A REASONED APPROACH TO HOW WE HANDLE GENETIC INFORMATION AND WE AVOID DISCRIMINATION IN THE USE OF THAT INFORMATION. SO, AGAIN, I CONGRATULATE SENATOR ENZI. I THINK SETTING THIS AS THE FIRST ITEM THAT HE HAS MOVED OUT OF THE HELP COMMITTEE UNDER HIS CHAIRMANSHIP REFLECTS HIS COMMITMENT IN MAKING SURE THAT HEALTH CARE IN THIS COUNTRY IS NOT ONLY OF A BETTER QUALITY BUT THE SCIENCE THAT BACKS UP HEALTH CARE CONTINUES TO BE ROBUST AS IT PERTAINS TO CURES FOR ALL AMERICANS.